



Crohn's and Colitis UK Policy Statement on relations with the pharmaceutical industry.

One of the principles underpinning the Crohn's and Colitis UK Vision is to forward the charity's objectives through research, development and service activities in partnership with Health Service, professional and other patient organisations and with the pharmaceutical industry.

Crohn's and Colitis UK recognises that the development, availability and proper use of medicines are an important part of the management of Inflammatory Bowel Disease (IBD). As the major IBD patients' organisation in the UK, it is therefore in patients' interests that the charity establishes effective liaison with pharmaceutical companies since the decisions they make will have a major effect on many patients' lives.

The purpose of this policy statement is to

1. explain why it is in patients' interests for Crohn's and Colitis UK to establish an effective working relationship with pharmaceutical companies and indicate to companies that the charity welcomes such a relationship;
2. make clear the Trustees' view of the principles that must underpin any communication or collaboration so that Crohn's and Colitis UK can work with companies without compromising its independence or reputation;
3. reassure members and the public of the charity's position;
4. enable the charity's staff to carry on their work without the need for constant reference to the Trustees.

The basis of the relationship must be:

- integrity and openness on both sides,
- respect by companies for the independence of Crohn's and Colitis UK
- recognition by Crohn's and Colitis UK of the need for commercial confidentiality on some matters,
- equality in any collaborative activities
- acceptance that the ultimate test for cooperation or collaboration will be what Crohn's and Colitis UK considers to be in the best interests of IBD patients.

Transparency and Financial Benefit

Crohn's and Colitis UK expects collaborative activities to be agreed in writing and declared by both parties. The Charity will set out in its Annual Report to the Charity Commission and on its website details of the support it receives from companies and of any collaborative projects.

The Trustees' policy is that direct financial benefit to the charity from pharmaceutical companies should not exceed 10% of the charity's overall income in any year.

Guidance on Collaborative Working

Crohn's and Colitis UK

- will not collaborate in activities that might tend to endorse a specific product or undermine a competitor product.
- prefers to work on major activities with consortia of two or more companies and seeks to avoid activities that are designed to give one company competitive advantage over another.

- will consider proposals against three factors:
 - Ethics
 - Desirability
 - Practicality (timing, resource etc) in relation to the charity's other plans and work.

Patient Education and Support

- Crohn's and Colitis UK supports the provision of information to patients about the treatments that are available and the discussion of available options to assist patients in making informed choices in collaboration with their health professionals.
- Where more than one branded version of a treatment exists, Crohn's and Colitis UK will expect any publication with which it is involved to use the generic name where possible or to refer to all equivalent available branded treatments.
- Crohn's and Colitis UK will consider collaboration on these provided
 - the information given is general to IBD and does not constitute explicit or implied product advertising or endorsement
 - they coincide with the education and support approaches that the charity wishes to see developed
 - they do not duplicate existing approaches and risk fragmenting the provision of consistent care to patients
 - the timing does not jeopardise the charity's other activities
 - the charity is consulted at an early stage in the development of the ideas
- Crohn's and Colitis UK does not formally endorse other organisations' literature.

Surveys and Research

- Crohn's and Colitis UK will consider undertaking collaborative patient surveys or focus groups provided these have
 - a sufficiently broad focus,
 - include information of value to the charity as well as the company,
 - conform to good market research standards
 - include a charity representative at any focus group
 and
 - there is a commitment to publish the results in an objective (peer-reviewed) format
- Crohn's and Colitis UK is willing to consider collaborative research proposals provided these coincide with its own research objectives.

Professional and Public Affairs

- There will be times when Crohn's and Colitis UK and Companies have shared policy objectives (e.g. increased allocation of resources for IBD or the introduction of new treatments)
- Crohn's and Colitis UK will consider joint working or collaboration in this area, but will require
 - objectives and the terms of the relationship to be agreed in writing at the outset
 - that independence or perceived independence of the charity should not be compromised
 - that there is complete transparency

Public Relations Activities

- Crohn's and Colitis UK will consider collaboration on these provided
 - the messages are general to IBD and do not constitute product advertising or endorsement
 - coincide with the messages the charity wishes to convey
 - the timing does not conflict with the charity's other media activities
 - the charity is consulted at an early stage in the development of the ideas

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